

Hearing Scheduled for Mar 10, 2015

Co-Chairperson: Greg Harris
Co-Chairperson: Robyn Gabel

Republican Spokesperson: Brian W. Stewart

Location: Rm 114

Subject Matter:
Barriers to Care and Isolation of Families

Greg Harris
Robyn Gabel

Brian W. Stewart
Mar 10, 2015 4:00PM
Room 114 Capitol Building
Springfield, IL

Barriers to Care and Isolation of Families

Clerk of the House:
Timothy D. Mapes

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BARRIERS TO CARE AND ISOLATION OF FAMILIES

From: Stacey M. Cole, Parent

Good afternoon.

First, thanks to Representative Harris, Representative Gabel, Representative Stewart and everyone in attendance today for allowing me to be here. It is a both a privilege and an honor to speak to you today; thank you for allowing me to share a very small fraction of our family's gut-wrenching mental health experience with my son, Kody.

"Imagine a better life for Kody" (<http://www.gofundme.com/2wwl80>)

"¢ Imagine the gentle child you raised becoming unpredictably violent to himself and others

"¢ Imagine your child refusing to come home and choosing to sleep on the streets. And, not knowing where they are or where their next meal is coming from

"¢ Imagine desperately seeking every available type of help. And, then reading a therapist's assessment that your child had been severely traumatized

"¢ Imagine the pain you'd feel learning that they had suffered in silence for years and wondering what else you could have done

"¢ Finally, imagine getting a call from a friend saying that your child allegedly committed a crime and had been arrested

"¢ Imagine the gut-wrenching suffering your family would negotiate feeling that maybe being in jail was the safest place for your child and your community

I don't have to imagine these things anymore. Now my family has lived through these pains.

Like many families in the U.S. we suffer from wounds that are not visible to others.

When our son Kody was young he experienced unimaginable trauma that he did not share with us. As he grew older he began to demonstrate unpredictable anger and rage. He was out of control. We tried therapists, medications and even short-term residential care. We tried everything we knew to get him the help he needed, but we quickly ran out of options. As a middle class family, many programs were more expensive than we could afford and our earnings made us ineligible for public assistance.

"¢ Imagine a future for Kody where he has received the treatment he needs and has avoided being sent to prison.

"¢ Imagine a future for Kody where he contributes to his community instead of being a liability to it.

"¢ Finally, imagine a future for Kody where he is empowered to negotiate his mental and behavioral challenges in appropriate ways that are not harmful to him or others.

I am an active, involved parent.

Kody has a history of unimaginable, extreme trauma (from birth to age 5). It wasn't until he reached age 17 that we found out his diagnosis: PTSD, mood disorder, NOS, severe depression and oppositional-defiant disorder (ODD).

He was irrational, impulsive, suicidal and dangerous to himself and others.

He needed support and there was absolutely nothing anyone would or could do to help me. No one knew what to do in our community. I felt completely helpless and lost.

I was literally begging the school and others to help us.

We were ignored by the school.

School wasn't addressing his needs.

He was 12 hours from being thrown in a prison from a juvenile court. The judge said "if you don't have a place for him, I do."

We had to hire a lawyer to finally get help.

Then I get that help, he gets discharged with very little help afterwards.

He was performing poorly in school; both academically and behaviorally.

We set up a crowd-funding website for support. I have people reaching out to me from all over the country saying how they are going through the same experience.

Access to resources are slim to none in our community and many others. The only access to resources we have in our community is a short-term hospitalizations and incarceration.

The process that it took to get him the help that he needed (and continues to need) was so incredibly gut-wrenching. Sucks the life out of you.

After months of research, I asked for our school to add "emotional disability" to his existing IEP.

Our school completely ignored the private neuro-psychological detailed evaluation.

They allowed Kody to select the class he would be observed in.

The school fought us *on his eligibility*, ... let alone services.

I took off work for 6 months

Middle class family – sold our belongings

Went to every single person I could get in front of – CEO's, mental health facilities, state-funded mental health programs, I stood in front of our community's mental health board. – no one could help me. Many told me there was nothing I could do. Well, except for give up my parental rights (Kody was 17) to DCSF and pray that he would get accepted into a residential treatment facility quicker.

I became clinically depressed;

I was functioning on fumes.

I learned the following very quickly:

Extended and excruciating pain will render you unconscious.

An example of how policy has failed our child because our school community was not properly tooled to educate our child because of his mental health issues and because of his disabilities.

After meeting with the school administrators for his IEP meetings and discussing proper educational planning for Kody, the school board refused to take any of our suggestions or requests and didn't put any into play.

Outcome ended up being an 18 year-old child who is legally blind, can barely read (or perform mathematically) at a 5th grade level but is receiving a high school diploma. The reality is that Kody has no real skill set, he is extremely under his progress level academically for his age. He is now 19 and is reading/performing math at an elementary school level. Further, our school system allowed my son to receive passing grades and graduate even though he hasn't earned them.

Who do we go to when we are asking for support from the school and we can't get any help?

We reached a point where he was in high school and his behavioral issues that we had been addressing started to grow into issues where it was clearly interfering with his education (receiving all D's and F's, suspended from school, banned from bus terminal, trouble with the law). The alternatives for education for a child with Kody's needs were ineffective. This didn't meet Kody's needs; it actually made things worse until things were spiraling out of control.

People reach out to me from all over the country sharing how they went through the same thing.

The school district failed him in educating him. Denied him "emotional disability" after WE asked for this to be added to his IEP. Further, the school said they would observe him in a "class of Kody's choice" by someone from within the school district and that

they would not accept the professional neuro-psychological report we just had completed – saying they do not accept anything external.

I remember this like it was yesterday....I told a table full of administrators during an IEP meeting that I felt Kody was behaving in such an irrational, impulsive manner that I was worried he could be capable of being the next Newtown shooter. The room got quiet and then my husband and I were told “Good luck. Keep us posted.” It was then I knew I **had** to do something.

I spent 6 months off work researching, making phone calls, sending emails, meeting with affluent members of the community.....and ended up going in a huge circle. No one knew what to do to help. My son was a liability to our community; he was suicidal. He would be dead had I not hired an attorney. The entire process was excruciating.

It seems as if we have a system that just wants to push problematic situations out as opposed to ensuring he was educated properly. He’s been able to pass every grade up until graduation, with complete disregard for our requests to hold him back and hold him accountable. Failing grades every quarter, missing assignments, psychological tests that say he is not where he is supposed to be academically. Yet he’s getting the same diploma that kids are granted access to colleges and universities with.

- Experiences with Kody –

Roadblock after roadblock:

Due to his age, lack of funding, lack of facilities, no bed availability, there were hardly any placements out here to get him the help that he needs.

The investment and the toll this has taken on our family. Emotionally, physically, financially – this experience turned our lives upside down and was very close to becoming a headline tragedy in our community.

We were literally down to 12 hours before Kody would be thrown in jail had we not hired attorneys who found a place for Kody to go and receive help. He needed more support.

Now, hes back in the community because there are little to no support. So, he is going straight from a locked residential facility back into our community because there are little to no placements available anywhere in this state.

This experience completely took over my life.

The 3 young men that Kody was hanging out with are now all dead... all from shootings.

So many families who don't have the access to taking time off work and who don't have ANY resources.

It is extremely difficult to explain the complete destruction this has done to me and my entire family, let alone Kody.

It diminished our quality of life.

Not All Wounds Are Visible.